Original article

Structural barriers in care nutrition for people with chronic kidney disease in Mexico

Barreras estructurales en la atención nutricia a personas con enfermedad renal crónica en México

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Abstract

This study describes the structural barriers that the health personnel identifies to provide nutritional care to people with chronic kidney disease. A qualitative study was carried out in San Luis Potosí, Mexico. We interviewed 21 health professionals (nutritionists, nurses and nephrologists) who work in hemodialysis units. Critical discourse analysis was performed. The study participants point out various structural barriers that hinder the inclusion of diet therapy in the treatment of CKD: the lack of universal health coverage in Mexico, which means that not all people with CKD have access to nutritional treatment; inadequate infrastructure in hemodialysis units, where nutritionists lack a physical space to provide appointment or advice; absence of regulations and protocols for nutritional care; lack of human resources in nutrition, specialized in CKD. In conclusion, it is highlighted that nutritional care for kidney patients in Mexico is incipient and little systematized. It is necessary to institute universal care, as well as modify the national regulations to include specialized nutrition personnel to interdisciplinary treatment for the benefit of those who suffer from the disease.
Keywords: Chronic Kidney Disease; Health Personnel; Diet Therapy; Qualitative Research; Mexico.

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Resumen

Este trabajo se propone describir las barreras estructurales que el personal de salud identifica para brindar atención nutricia a personas con enfermedad renal crónica (ERC). Se llevó a cabo un estudio cualitativo en la ciudad de San Luis Potosí, México. Se entrevistó a 21 profesionales de salud (nutriólogos, enfermeras y nefrólogos) que trabajan en unidades de hemodiálisis. Se realizó un análisis crítico del discurso. Los participantes del estudio señalan diversas barreras estructurales que obstaculizan la inclusión de la terapia nutricional en el tratamiento de la ERC: la falta de cobertura universal de salud en México, lo que genera que no todas las personas con ERC accedan a un tratamiento nutricio; la infraestructura inadecuada en las unidades de hemodiálisis, donde los nutriólogos carecen de un espacio físico para dar consulta o asesoría; la ausencia de normativa y protocolos para la atención nutricia y; la falta de recursos humanos en nutrición especializados en ERC. Como conclusión, se destaca que la atención nutricia para los enfermos renales en México es incipiente y poco sistematizada. Se requiere instituir una atención universal, así como modificar la normativa nacional para incluir al personal de nutrición especializado en el tratamiento interdisciplinar en beneficio de quienes padecen dicha enfermedad.

Palabras clave: Insuficiencia Renal Crónica; Personal de Salud; Terapia Nutricional; Investigación Cualitativa; México.

Introduction

Chronic Kidney Disease (CKD) is a global public health problem. It is estimated that about 500 million people worldwide suffer from this disease and just over 3 million are terminally ill (Roberti et al., 2018).

In Mexico, the number of people with CKD has increased, mainly associated with the incidence of diseases such as diabetes mellitus and hypertension, (García-García; Agodoa; Norris, 2017), as well as the trend towards population aging.

The increased incidence and prevalence of CKD leads to increased demand for the services offered by the health system, which, to date, have been documented as insufficient, and have even been excluded from a significant number of renal patients (Carrillo-Larco; Bernabé-Ortíz, 2018; Mercado-Martínez; Correa-Maurício, 2015; Roberti et al., 2018), since they generated inequities in accessing services, where access is understood as 'the degree to which individuals or groups of individuals have the ability to obtain the necessary care of the provided medical care' (Laurell, 2016; López-Arellano; Jarillo-Soto, 2017). Not to mention the increase in the economic, social and emotional costs implied by this suffering (Díaz-Medina; Mercado-Martínez, 2019; Mercado-Martínez; Hernández-Ibarra, 2016).

Interest in studying CKD has increased in recent years; however, the perspective of health professionals has been prioritized from an eminently biomedical approach. In contrast, there are few studies that address the issue from a qualitative approach and incorporate the voice of sick subjects, their caregivers and the health workers who care for them (Mercado-Martínez; Hernández-Ibarra, 2016; Mercado-Martínez et al., 2014; Tong et al., 2013; Wong et al., 2018), and even more scarce are the research that has specifically explored the issue of nutritional therapy and feeding in treatment from the perspective of people with CKD (Hernández-Ibarra; Martínez-Castañeda, 2016; Suchil; Hernández-Ibarra, 2016).

Nutritional treatment is essential, since it delays the progression of kidney damage and prevent the occurrence of some of the most common complications, the same ones that usually arise

among the main causes of morbidity and mortality in those who suffer from it. However, most studies often explain and address the phenomenon in terms of restrictions and adherence to treatment, including diet that, in our opinion, blames people who have it and leaves aside other situations that function as barriers or obstacles to access nutritional treatment, a primary issue in terms of management and control in CKD (Bousquet-Santos; Costa; Andrade, 2019; Kalantar-Zadeh et al., 2015; Mayoral; Martínez Rincón, 2015).

This research describes the structural barriers that health professionals identify as an obstacle to nutritional therapy being provided to people with CKD. We understand as structural barriers all conditions that derive from the State, through their public and government policies, which delay, prevent and hinder the recovery of human health or the limitation of damage. Health professionals play a key role in the management and control of the disease, including the nutritional therapy of those with CKD. Scientific evidence suggests that nutritional therapy may serve as a barrier (Chen et al., 2016; Terranova et al., 2017) or as a facilitator in care (Lambert; Mansfield; Mullan, 2018; Terranova et al., 2017).

For this study, we adopted a critical-interpretive perspective (Mercado-Martínez, 2002), to explore the subjective and experiential world of suffering, as well as the material and social context that surrounds it. This epistemic and methodological approach obliges the researcher to a position of permanent self-reflection and deconstruction, which requires him to recognize the existence of contexts of inequality and injustice and, as a result, explain the origin of these context, a situation that continually leads the researcher to recognize the relevance of everyone involved in social events, particularly those of the people who make up the historically vulnerable groups.

Two notes on the context

Since its inception, the Mexican health system has been fragmented and unfair, while half of the population has social security thanks to having formal employment and being dispensed by the employer, less than 10% have access to private medicine, usually those able to afford it and others who are served by a popular insurance care system (Laurell, 2016). This is a public and voluntary health plan, with almost 52 million associated people; however, it excludes coverage of diseases such as chronic renal failure and renal replacement therapies such as hemodialysis, peritoneal dialysis and kidney transplantation (Mexico, 2019). As a result, people with the disease and their families are forced to cover costs, which results in personal expenses.

Despite having institutions and agencies responsible for collecting and presenting information and health statistics, such as the Department of Health itself, there is still no national record of people with chronic kidney failure in Mexico. There are some efforts at local level in some states, but this remains a pending issue (Prensa el Jue, 2019).

Material and methods

This study is derived from a more comprehensive one, which explored the experiences of people with CKD, and those of their families, in relation to the care they receive. This study explores the perspective of health personnel who treat people with kidney disease, while qualitative studies are interested in knowing and understanding all social actors involved in certain phenomena.

A qualitative study was conducted in the city of San Luis Potosí, Mexico. The informants were selected by a proposed sample. This sample consists of cases that, in advance, due to their characteristics or experiences, are known to represent the greatest possible wealth of information about the phenomenon investigated (Patton, 2002). This type of sample involves a series of steps: first, clarify what types of knowledge or experience participants should have; and, secondly, identify where they are located. (Mendieta Izquierdo, 2015).

Twenty-one health professionals participated. Six nutritionists, two dietitians (one with a specialty in nephrology), eight nurses and five nephrologists from seven hemodialysis units in the city, of which three public and four private.

Four nutritionists worked in public hemodialysis units; the other two, in both public and private units.

The two dietitians worked in the public sector. Half of the nurses worked in public units; and the others, in private units. Of the nephrologists, two worked in the public sector; and three, both in the public and in private.

Between June 2016 and May 2017, we conducted semi-structured interviews with participants in hemodialysis units. These interviews lasted about 60 minutes each. An interview guide was followed based on the literature review; divided into four parts: introduction, approximation, deepening and synthesis/closing. This guide included detoxify questions such as "what are the main problems you face in treating people with CKD?" and "if it were in your hands, what would change about the nutritional care provided to people with CKD?" At the end of the interviews, a summary of what was addressed to the participant was addressed to verify the information and make the necessary clarifications.

The interviews were recorded in audio by prior informed consent and were later transcribed by the first author, in pre-established format. For the analysis, the information was organized in the Etnograph V 6.0 program. Two authors (NR and EH) were responsible for the processing of information and, with the other authors, participated in the review of materials, coding and identification of emerging themes, as well as in the selection of fragments of the text to exemplify with quotes, and in writing in general.

Once the transcripts were validated by the second author, a critical analysis of the discourse was performed. To obtain codes and categories, the three areas proposed by Fairclough (2003) were considered, as well as the objective of the study. The analysis began with the general reading of the interviews to immerse in the theme, explore what is said by health personnel, themes, dimension and context in which they are perceived. A line-by-line reading of the recorded interviews continued to identify the voice of social actors in their daily experiences, their position in the social context and in relations with others. It should be noted that, in this article, only the results belonging to the structural sphere are addressed.

In this study, the ethical principles established in the Declaration of Helsinki were fulfilled. The autonomy and self-determination of the participants were respected at all times and confidentiality and anonymity have also always been respected. The research from which this article is derived was approved by the Ethics Committee of the Universidad Autónoma de San Luis Potosí and obtained the registration CEIFE-2015-132.

Results

This study shows discourses of nutritionists, nurses and nephrologists involved in the treatment of people with CKD who receive hemodialysis. The discourses of the dietitians were included in the analysis of the nutritional group because it was part of the nutritional staff of health institutions.

From the point of view of those who participated in this study, a set of situations in health services has a negative impact on people with CKD to do nutritional therapy that helps to obtain better results in their treatments and who, as a result, improve their health condition, quality of life and reduce possible complications.

Lack of coverage

For study participants, one of the main obstacles that prevents people with CKD from accessing nutritional therapy is that not everyone has the same coverage or social security. In such circumstances, people with this disease have to pay for some care they need from their own pocket, prioritizing renal replacement treatment and some medications, which leads them to choose between: adhering to a hemodialysis session, paying for medicines or go to nutritional appointment. A participant expressed as follows: *We have patients of all economic levels and patients who do not have social security, patients who barely have to pay for a hemodialysis, right? They either pay for hemodialysis, or pay for erythropoietin, or eat* (nutritionist).

Inadequate infrastructure

In addition to the lack of coverage, another barrier in both public and private institutions, according to the participants, is that, in hemodialysis

units, there is no room for exclusive nutritional appointment for people with CKD.

The units located within hospitals face similar situations because they do not have physical space or sufficient staff. When there is a nutrition office, this service is not specific to kidney patients, but it is for the whole hospital. Then one of the physicians expresses: *We don't have a nutrition office...* [...] *in the afternoon the intern* [student in nutritional practices] *arrives at the office next door, cardio, and gives the appointment* (nephrologist).

They are the same health professionals who work with strategies to try to remedy the lack of infrastructure and staff, while reaching students in their last year of training, this is the case of interns who do not yet have the knowledge or skills necessary to provide care to CKD patients.

Lack of regulations and protocols for nutritional care

In hemodialysis units where the study was conducted, the inclusion of nutritional therapy in the treatment of people with CKD is not systematized or lacks a protocol to follow, this is seen both in public and private units.

This situation means that, in most units, access to nutritional care depends primarily on the judgment and will of the doctor; and, secondly, the recommendations that nurses make to sick people or their families. It was found only in a private unit, that the reception staff is responsible for channeling, from the beginning, the person with CKD to the appointment of nephrology and nutrition. On the other hand, it is sometimes the same patients or their families who request to be sent to the nutritionist. So one of the nephrologists justified the reason why it does not channel the sick person to the nutritionist: *I do not believe in the* [usefulness of] *nutrition, so I never send my patients, I do it only when they ask me* (nephrologist).

Due to the lack of systematization or protocols of the inclusion of nutritional therapy in the treatment of CKD, referral cannot be done or presented late, that is, when the person presents complications as a result of spending a lot of time "out of control." This last term usually arises in the speech of professionals when alluding to people with high levels of potassium, phosphorus, sodium or when they have edema. That is when they decide to ask nutrition personnel to treat people with CKD.

Insufficient human resources

Participants emphasize the lack of people in the staff that provides care to those who live with CKD and even mentions the need to incorporate professionals from various areas. They point to the inclusion of the nutrition staff as necessary, but also allude to the importance of increasing the number of physicians and nurses.

Not all hemodialysis units have a nutritionist who provides care. Those who count on this professional often face the saturation of the service, that is, long waiting periods before people with CKD can meet the nutrition personnel. An informant refers to the latest situation as follows:

> *Send* [the nephrologist] *patients to the nutrition clinic, I think there are two* [nutritionists] *for the whole clinic, so the appointments are very outdated from when the patient requires it* [...] *the patient is here and in 4 or 5 months, they will see nutrition.* (nurse).

Professionals working in units with nutritional services point out as a limitation of nutritional therapy the fact that it has to take months for the necessary care to be provided; this factor often discourages them from referring those suffering with CKD to nutritional service.

As a strategy to address the lack of nutritionists in hemodialysis units, the same staff suggests that, if it is not possible to hire graduated people, universities could manage to incorporate undergraduate interns in nutrition as a measure to alleviate the lack of staff and thus provide care to these patients. One of the informants says:

> *We ask this over and over again, but by the theme of budgeting and availability of vacancies, we could not have a dedicated nutritionist exclusively at the service of nephrology, but we should have at least one nutritionist who was working here, side by side,*

with the integral management of patients we see in the different stages. (nephrologist).

Especially in the public sector, the lack of nutrition personnel has created an excessive workload due to the many activities that must be carried out, including the survey of morning censuses, the valorization of people in the internal medicine service and the external appointment, among others. This phenomenon makes insufficient the time spent in nutritional therapy, so sometimes employees have to limit themselves, therefore, to verbal guidance of diet characteristics to patients. One of the nutritionists puts it as follows:

The functions must be fulfilled, not only the appointment, but also [...] *in internal medicine, which is where kidney patients are most attended and, moreover, have to be support in the preparation of censuses, diets. It is not only appointment, other functions must be fulfilled, and a single nutritionist takes care of all the renal problems, it is insufficient.* (nutritionist).

In turn, the nephrologists interviewed allude not only to the lack of staff, but also to the lack of knowledge of nutrition professionals for the care of those with CKD. For them, it is necessary that nutritionists working with kidney patients have a specialization in nephrology that evaluate their knowledge. Then one of the physicians talks about it: *What usually happens is very similar to what happens to us, physicians, we don't have the nutrition staff specialized in the disease and, thus, there are many confusions* [the nutritionists] *regarding the prescription of the diets* (nephrologist).

For nephrology staff, the profile of nutritionists is insufficient; some say that in order to be well prepared, nephrologists should participate in the formation of nutrition graduates. Thus, one of the professionals referred: *How will [the nutritionists] know about nephrology if no nephrologist taught them?* (nephrologist).

The disbelief and little confidence of nephrologists in the relevant knowledge of nutrition professionals become another aspect that often limits the inclusion of nutritional therapy in the treatment of people with CKD. This mistrust creates resistance in putting "their patients" in the hands of professionals who do not consider prepared to provide treatment.

Discussion

This study aimed to describe the structural barriers that participants, health professionals, identify as an obstacle to the provision of nutritional care to people with CKD.

According to the findings, multiple barriers prevent adequate nutritional care for people with CKD in Mexico. Situations that limit or prevent such care include characteristics of the health system structure in Mexico, as well as the institutions where hemodialysis units are located and even in the units themselves.

The participants' discourses reveal that the care for kidney disease is mediated by the fragmented structuring of the Mexican health system, deep fragmentation starting from the last neoliberal health reform that gave rise to the creation of the National System of Social Protection in Health, better known as Popular Insurance (Laurell, 2016; Mercado-Martínez; Hernández-Ibarra, 2016). As explained in the context, those who receive care in the first subsystem (formal workers and their families, 39.2% IMSS, 7.7% ISSSTE of the total population) have coverage of renal replacement therapy, in addition to economic benefits, sickness and pension benefits. In the second subsystem, also known as Popular Insurance, intended for non-formal employment (49.9% of the national population) (Inegi, 2015) does not have free access to any renal replacement therapy, much less nutritional care, and the cost of care will depend on a socioeconomic study (Mexico, 2019).

The lack of coverage of CKD treatment shows, to some extent, the inability of the Mexican health system to provide universal care, which makes most people who have this disease have expenses of their own pockets, including devastating expenses to receive necessary care (Mercado-Martínez et al., 2014).

This situation has been discussed and highlighted before. To cite an example, the Organization for Economic Cooperation and Development (OECD)

mentions that fragmentation that characterizes the Mexican health system is also its most important problem (OECD, 2016). Those who participated in this study mention that this causes each of the health institutions to offer care aimed at different groups, with different coverages and, therefore, different results. Other authors are more direct and point out that this issue exemplifies the social and health inequalities that have brought health reforms with neoliberal brands and that have the effect of dismantling public health and social security institutions (Baru; Mohan, 2018; López-Arellano; Jarillo-Soto, 2017).

It is known that high out-of-pocket spending on Mexican health indicates precisely a failure of the health system to achieve coverage and high quality services (Laurell, 2016). The professionals interviewed reinforce this point, alluding to the constant attestation to situations in which people are forced to decide between paying for a hemodialysis session, medications or nutritional therapy, due to the high cost of the treatment for those who do not have social security services and even for those who are affiliated with Popular Insurance, since it does not cover treatment.

This reality is far from that of countries with universal health coverage, such as Brazil or Uruguay, where population studies with CKD and the barriers identified in the Mexican context (Mercado-Martínez) are not reported; Levin-Echeverri, 2017).

Although all units we visit have a physical space for the specialist physician to make the appointment, it does not apply to the spaces necessary to provide nutritional care. In addition, there are units that lack nutrition personnel while, in those who have it, usually, it is usually in insufficient numbers, a single professional to attend to all people who receive hemodialysis sessions.

Significant gaps have long been reported in relation to the care of this group (Treviño-Becerra, 2004). According to the author, Mexico does not have the infrastructure or human resources to meet the needs of those living with CKD. This situation was observed at the beginning of 2000 and, almost two decades later, little has changed, even if it requires more spaces and more prepared staff, not only physicians, but also nutritionists, because the number of people with CKD continues to increase.

Another aspect to be discussed concerns the organization or administration of the units. More specifically the lack of systematization, protocols and institutionalization of nutritional therapy in the treatment of CKD, a situation that gives rise to the judgment and will of the physician who deals with the theme and, secondly, of nursing staff who are in contact with people during hemodialysis sessions.

For clinical care of people with CKD, the medical team follows the guidelines set out in the Clinical Practice Guide for the prevention, diagnosis and treatment of Early Chronic Kidney Disease, which is based on what was established in K/DOQI Clinical Practice Guidelines for Chronic Kidney Disease. This document makes a compendium of evidence, among which highlights the deterioration that suffers the nutritional status of the person with CKD during the course of the disease, recommends promoting adequate nutrition in this population group and incorporates the need to include nutrition staff in the care protocol. However, it should be mentioned that the document only establishes general recommendations, which does not define the course of conduct of professionals.

Another document establishing guidelines in clinical management of the disease is the Official Mexican Nom-003-SSA3-2010 for hemodialysis, points out that providing replacement therapy along with medical and nutritional measures helps improve the prognosis and modifies the evolution of the condition and favors the chances that the person enjoys a better quality of life. This standard leaves the nephrologist responsible for the full treatment of the disease, because he considers that he is the one who should do the medical evaluation, request the necessary laboratories and cabinet studies, provide the necessary nutritional measures, as well as request the psychological evaluation when necessary (Mexico, 2010).

The delegitimization that both documents printed on nutritional therapy and nutritional staff may be related to the biomedical and care approach that characterizes the Mexican health system, in which the curative methods by the medical team are prioritized on preventive factors, such as the change of eating habits. This situation is reflected not only in the health system, but also in institutions that

train new professionals, where young people are educated according to a curative and care approach, which focuses on high-specialty medical care and ceases to health areas focused, by their nature, on preventive measures and health promotion.

Final considerations

As the study participants point out, protocol to the inclusion of nutritional therapy in the treatment of CKD could largely ensure that people living with the disease receive such a therapy. Health measures should be stipulated to provide hemodialysis care, so it is impossible to include nutritional procedures, which show their importance in multidisciplinary treatment and, with the aim of comprehensive care, in which, likewise, themes of psychology, social work, physical activity are addressed, among other disciplines so far not accessible to people with this disease.

Although what has been exposed here offers a picture of barriers and obstacles to include nutritional therapy in the treatment of people with CKD who receive hemodialysis in the city of San Luis Potosí, this research never occurred with the aim of generalizing in the but some of the findings could be applied to other contexts, since we share the same health system throughout the national territory, as well as some similarities with other health systems in Latin America, except those that have a universal system, such as Brazil and Uruguay, which could have barriers of a different nature from that reported here.

Finally, it is desirable to complement this perspective with the voices of other actors involved, such as managers, family members, administrative and operational staff. The strategy used was the semi-structured interview, which means that, here, the voice of the participants has been prioritized on other elements that could give tips to better understand the care, such as asking if the speeches correspond to everyday practices.

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Authors' contribution

Hernández-Ibarra was responsible for the study conception. Roses-Cortez collected the information. Both authors analyzed and participated in the writing of the article. Zillmer, Rangel-Flores and Gaytan-Hernández contributed to the analysis and writing of the article.

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